



Dementia in Canada

Presentation to the Standing Senate Committee on Social
Affairs, Science and Technology

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Overview of Recommendations

Recommendation 1: The federal government collaborate with the provinces/territories to negotiate a new multi-year Health Accord that:

- Enforces the principles and spirit of the *Canada Health Act*;
- Increases federal-provincial/territorial funding;
- Advances interprofessional primary care with RNs, NPs, and all other health professionals working to full scope;
- Reinstates the Health Council of Canada; and
- Expands Medicare to include all medically necessary areas, starting with universal home care and pharmacare without co-payments or user-fees.

Recommendation 2: Support efforts to advance a timely diagnostic process for persons experiencing dementia, including the full utilization of RNs and NPs and access to specialized assessment services.

Recommendation 3: Ensure the appropriate supply, distribution and utilization of RNs and NPs in Canada to effectively support persons living with dementia, including specialized roles such as geriatric emergency management (GEM) nurses, psychogeriatric specialists, and clinical nurse specialists in gerontology and/or mental health.

Recommendation 4: All RNs must complete mandatory gerontology and chronic disease management training in entry-to-practice curriculum including clinical experience with geriatrics.

Recommendation 5: Support efforts to enable independent RN prescribing in Ontario and use this as a framework for expansion across the country.

Recommendation 6: All unregulated care providers complete mandatory geriatric and CDM training that includes:

- Communication and documentation skills;
- Collaboration and team work;
- Effective management of responsive behaviours; and
- Person and family centred care and services.

Recommendation 7: Provide human and financial resources to support uptake in practice and education, of the most current and relevant evidence to ensure the highest quality, evidence-based care for Canadians with dementia.

Recommendation 8: Ensure that all Canadians with dementia, regardless of their socioeconomic status, have access to appropriate housing. This can be done by ensuring that accessible housing models exist that accommodate various levels of care needs and abilities, and resembles living at home.

Recommendation 9: Apply a health equity lens in government decision-making to better understand the sociocultural and economic factors that persons with dementia and their care partners' experience.

Recommendation 10: Recognize and value the integral role of care partners for persons experiencing dementia and ensure structured support exist, including accessible day programs and respite care.

Recommendation 11: Support efforts that co-ordinate information about local services and programs under one body. Features of the services and programs should be clearly communicated to the public (i.e. provision of meal, length of session, age requirements, etc.).

Recommendation 12: Advance federal initiatives to support provinces/territories to make interprofessional primary care teams the foundation of their health system. Locate and embed care co-ordination and dedicated care co-ordination RN roles within primary care.

Dementia in Canada

Background

The need to prevent and manage dementia in Canada is critical. In 2011, 747,000 Canadians lived with Alzheimer's disease and other dementias (ADRD). This amounted to 14.9 per cent of Canadians 65 and older (Alzheimer Society, 2012). By 2031, the number of Canadians living with dementia will increase to 1.4 million (Alzheimer Society, 2012). Dementia does not discriminate. It impacts people of all socioeconomic classes, genders, ethnicities, and is not just a disease of older persons. For example, roughly 1 in 1000 people under the age of 65 develop dementia (Alzheimer Society Canada, 2015). The impact of dementia can be felt at all levels of our society. The significant stigma associated with dementia creates further barriers to the access and delivery of high quality care and services. An urgent focus on living well with dementia is needed.

The **Canadian Gerontological Nursing Association (CGNA)** is the national organization representing gerontological nurses and promotes gerontological nursing practice across national and international boundaries. In 2010, the CGNA developed care competencies for gerontological nursing, including competencies to provide care for seniors with dementia.

The **Registered Nurses' Association of Ontario (RNAO)** is the professional association representing registered nurses (RN), nurse practitioners (NP) and nursing students in Ontario. RNAO has extensive expertise in the area of dementia care. In particular, RNAO developed two clinical practice guidelines that are widely used.

- Screening for Delirium, Dementia and Depression in the Older Adult (RNAO, 2003)
- Caregiving Strategies for Older Adults with Delirium, Dementia and Depression (RNAO, 2004)
- Person-and Family-Centred Care (RNAO, 2015A)

RNAO and CGNA are pleased to deliver a joint submission and appreciate the opportunity to inform the Standing Senate Committee on Social Affairs, Science and Technology as it reviews and reports on dementia in Canada. This submission will provide background and recommendations on five key areas related to dementia care in Canada: health system resources, education and training of health professionals, housing, care partners, and the integration of health and social services.

1. Health System Resources

Dementia is a highly complex illness that encompasses responding to biomedical, psychosocial and ethical challenges (Aminzadeh, Molnar, Dalziel, and Ayotte, 2012). It has various pathophysiologies and manifests through a range of symptoms where individuals experience memory deficits, reduced cognitive skills and an inability to perform the activities of daily living (Alzheimer's Association, 2016). This multifaceted illness requires a multifaceted approach which includes various health and social services. It also requires health human resources equipped with the knowledge and skills to manage this chronic disease.

1.1 Medicare

Canada's publicly funded and not-for-profit health system is a cherished and valuable public asset that uniquely positions it to effectively respond to the growing numbers of people living with dementia, as well as their care partners. Effectively supporting Canadians living with dementia, as well as their care partners (family members, informal care givers), requires resources both within institutions and the community. In 2001, less than 10 per cent of senior women and five per cent of senior men resided in health-care institutions (Cranswick & Thomas, 2005), and in 2002 more than two million Canadians over the age of 45 were caregivers for seniors with long-term health conditions (Statistics Canada, 2008). Thus, more people with dementia are living within their communities, and most of their care is provided by family, friends and significant others. Despite strong evidence for the cost-effectiveness of home care

and the importance of home support services as a substitute for the more expensive services provided in long-term-care facilities (Béland, 2007; Greenwood, 2006; Hébert *et al.*, 2007; Hollander, 2001; Hollander *et al.*, 2002; Landi *et al.*, 1999; Landi *et al.*, 2001; Pedlar, 2006; Rigg, 2006; Scuvee-Moreau *et al.*, 2002; Stuart & Weinrich, 2001; Weissert *et al.*, 1997), Canada spends only 3.5 per cent of its public expenditure on home care. This ranks among the lowest of all member countries of the Organisation for Economic Co-operation and Development, with only 3.5 per cent of public health expenditures directed towards home care (Health Council of Canada, 2006). Home health care and support services, along with pharmaceuticals, are not currently included under Medicare and this represents a significant gap.

The time to expand Medicare through parallel legislation to the *Canada Health Act* is overdue. Tommy Douglas' vision of Medicare was to cover drugs, dentistry, vision, home care and most other health services. In 1997, the National Forum on Health called for protection of the single-payer model and "...expanding publicly funded services to include all medically necessary services and, in the first instance, home care and drugs." In 2002, the Romanow Commission recommended expanding Medicare to include home care. Canada's Parliamentary Committee on Palliative and Compassionate Care called on the federal and provincial governments to "...implement a right to home care, long term care and palliative care, for all residents of Canada, equal to the current rights in the *Canada Health Act*." All of these expansions are necessary to provide effective holistic care to Canadians and their families living with dementia. With the federal and provincial/territorial health ministers engaged in dialogue regarding the future of the health system, it is imperative that a new Health Accord is negotiated that enforces the principles and spirit of the *Canada Health Act* and includes effective increases in funding. Moreover, it is critical to reinstate the Health Council of Canada (HCC), which was eliminated by the previous federal government, to serve as an independent national agency that monitors and assesses Canada's health system.

Developing a national strategy is critical to advancing dementia care in Canada. A national home care framework, along with national standards to support its implementation, would ensure that all Canadians have access to appropriate, publicly-funded, high-quality, not-for-profit, timely services and can maintain a consistent relationship with a care provider, regardless of where they live or the environment in which their care is provided. The necessary services should be available with a seamless transition for persons with dementia, their support system and care partners between levels and settings of care. National standards would address the inconsistencies in program goals, care providers, eligibility criteria, costs, and types of service that currently exist across provinces and regions. The national framework could include features such as single point of entry through primary care, comprehensive assessment of persons with dementia and their care partners, full scope of practice utilization of interprofessional teams and integrated care management (rather than case management) that includes the broad determinants of health. In tandem, national organizations like the HCC must be empowered to disseminate innovative practices and recommendations to sustain Medicare. The HCC could be tasked with reviewing the delivery of care and support services for persons with dementia and their care partners and using its finding to disseminate best practices and areas for improvement.

At the clinical level, less than half of individuals with Alzheimer's disease and/or their caregivers (45 per cent) report being told of their diagnosis (Alzheimer's Association, 2015). Research indicates the majority of people living with dementia have not received a formal diagnosis. In high income countries, only 20-50 per cent of dementia cases are recognised and documented in primary care (Dementia Statistics, Alzheimer's Disease International, 2015). Dementia diagnoses can take months or years to confirm and studies have demonstrated that the disease is pervasively under-detected, diagnosed, disclosed, treated, and managed in the early stages (Aminzadeh *et al.*, 2012). Delays occur between the time dementia is suspected and reported to a physician, during the wait to see a specialist, and while undergoing the testing period (Aminzadeh *et al.*, 2012). This questionable access to timely diagnosis is troubling, since a diagnosis of dementia is often needed to trigger necessary community resources. Memory clinics also

frequently have long wait lists, which further limits access. More attention must be given to improving the diagnosis of dementia; and the full utilization of NPs and RNs will be critical to supporting this.

Recommendation 1: The federal government collaborate with the provinces/territories to negotiate a new multi-year Health Accord that:

- Enforces the principles and spirit of the *Canada Health Act*;
- Increases federal-provincial/territorial funding;
- Advances interprofessional primary care with RNs, NPs, and all other health professionals working to full scope;
- Reinstates the Health Council of Canada; and
- Expands Medicare to include all medically necessary areas, starting with universal home care and pharmacare without co-payments or user-fees.

Recommendation 2: Support efforts to advance a timely diagnostic process for persons experiencing dementia, including the full utilization of RNs and NPs and access to specialized assessment services.

1.2 Health Human Resources

An ample supply, distribution and utilization of health professionals working together in teams is critical to support people living with dementia. Canadians receive the best care when it is provided through an interprofessional team where all members are enabled to practise to the full extent of their knowledge, skills and competencies. The previous Health Accord made interprofessional primary care a staple and this resulted in substantial progress in this initiative throughout the country (Health Canada, 2006). In Ontario, it led to the expansion of community health centres and the creation of NP-led clinics and family health teams.

More RNs and NPs are needed in all areas of Canada's health system to support persons experiencing dementia, including public health, primary care, hospitals, home care and long-term care (LTC) environments. A recent report from the Canadian Institute for Health Information (CIHI) shows that Canada's supply of RNs declined (-1%) in 2014 for the first time in almost two decades (-1%). In Ontario, there were 714 RNs for 100,000 people compared to 836 per 100,000 across Canada (RNAO, 2015B). This means Ontario has the second-worst RN-to-population ratio in the country. As part of its 2015 Federal Election Platform, RNAO called on the next federal government to earmark funding to increase RN and NP-to-population ratios (RNAO, 2015C). These findings raise significant questions about the province's ability to adequately meet the care needs of persons living with dementia in a person-centred manner.

LTC is one area where these issues arise. Residents in LTC and those soon to move into LTC settings, are older with increasingly complex co-morbid conditions (including dementia) compared to the resident profile years ago (Hirdes *et al.*, 2011). Skilled staffing is necessary to provide competent, dignified, and high-quality care to frail older people and their families (Cardona *et al.*, 1997; Stone & Wiener, 2001; Gaugler *et al.*, 2009). Thus, there is an increasing need for more RNs employed in LTC settings to care for this increasing complex population (McGilton *et al.*, 2016). RNs have proven to have a strong influence on resident and staff outcomes (Dellefield *et al.*, 2015; Dorr, Horn & Smout, 2005; Decker 2008; McGilton *et al.*, 2007). Providing direct care and working with licensed practical nurses (LPNs) and personal support workers (PSW), the effectiveness of the RN has been shown to be pivotal in determining the overall quality of care provided. A recent literature review described the current evidence as suggesting that a higher ratio of RNs to other nursing personnel in LTC improves quality of life outcomes for residents (Dellefield *et al.*, 2015), reduces the probability of hospitalization (Dorr, Horn & Smout, 2005; Decker 2008), and improves the quality of work environments for staff (McGilton *et al.*, 2007).

NPs can also make a significant difference in LTC. Within Ontario, the provincial government has shown tremendous leadership and has committed to funding 70 attending NP positions in LTC (MOHLTC, 2015). This is a positive step forward and needs to be expanded within the province and throughout the country.

Recommendation 3: Ensure the appropriate supply, distribution and utilization of RNs and NPs in Canada to effectively support persons living with dementia, including specialized roles such as geriatric emergency management (GEM) nurses, psychogeriatric specialists, and clinical nurse specialists in gerontology and/or mental health.

2. Education and Training of Health Professionals

A variety of interdisciplinary health-care providers care for people with dementia and their families. Nursing comprises the largest regulated health care workforce and nurses are deployed across all sectors of the health system (CNO, 2015). Nurses will encounter persons experiencing dementia in all types of care and home settings. Nurses and unregulated care providers provide the bulk of direct care services for people with dementia and their families making it critically important they have the knowledge and skill to provide high quality care. There is an opportunity to enrich the knowledge, skill and competencies of RNs and NPs related to dementia both within their initial education and through continual learning and professional development.

2.1 Education and Training of RNs and NPs

Overall, the literature shows a general lack of understanding of gerontological competencies among both nursing students and faculty (McCleary et al., 2014). As a result, the field of gerontology is often deemed undesirable by health and social service professionals. In particular, a negative perception of gerontological practice remains a longstanding issue among some nurse educators (Hirst, Lane, & Stares, 2012). Some studies show that nurses and nursing students believe that the field of gerontology inhibits the advancement of nursing skills and practice. Moreover, nurses perceive geriatric nursing to be overly complex due to the need to understand and respond to age-related health conditions and complexities (Gould, Dupuis-Blanchard, & MacLennan, 2013).

In addition, reviews have highlighted that gerontological content is insufficient in nursing education (Baumbusch and Andrusyszyn, 2002; Earthy, 1993; Kassalainen et al., 2006; McCleary et al., 2009). There may be many reasons for this deficiency, including faculty that is either not supportive or does not have sufficient gerontological expertise, the perception that gerontological content is an extra requirement, and the assumptions that such content is already integrated throughout the program. Hirst and colleagues (2016) suggested that nursing curricula must consider the needs of the older population and students should be educated on older adults' psychosocial and mental health needs as well as common geriatric syndromes such as dementia, delirium and responsive behaviours. Faculty members must also be equipped with the knowledge and awareness of the differences between younger and older adults in order to teach students about older adults and provide proficient clinical supervision (Hirst & Lane, 2016; Andrews et al., 2009; Smith, Spadoni, & Proper, 2013).

To adequately support RNs and NPs in their practice, curriculum content and continuing education needs to be:

- Interactive and multimodal with an emphasis on the application of the new knowledge.
- Reinforced and refined at the point-of-care by strategies, tools, and mentorship
- Supported by trained champions or clinical experts and by leadership and administrators.

Example areas of education include:

- Fostering gerontological nursing knowledge

- Managing of personal expressions, behavioural and psychological symptoms of dementia
- Developing communication skills to engage persons experiencing dementia
- Understanding the importance and boundaries of care partner engagement
- Fostering attitudes and knowledge conducive to the care of persons experiencing dementia
- Recognizing the importance of chronic disease management for those with dementia
- Prevention and management of abuse and neglect of older persons
- Advocating for the delivery of person-centred care
- Understanding and appropriately responding to the generational differences with people experiencing early-onset dementia
- Promoting meaningful activities for those living with dementia
- Awareness of the social and financial support systems for people with dementia and their care partners in a variety of settings
- Understanding the differences between dementia and other mental/medical issues (i.e. delirium, depression, bipolar disorder, etc)
- Strengthening advocacy and leadership in the care for people with dementia
- Supporting people with dementia and their families with advanced decision making at end of life
- Accurately documenting behaviours exhibited by people with dementia (i.e. exit seeking, tracking, etc)
- Effectively responding to people with dementia as their physical and cognitive needs and resultant behaviour changes. Programs such as Gentle Persuasive Approaches and PIECES could be used.

There is also an opportunity to examine the role of the RN to ensure that it is effectively meeting timely access to care and health services. There is growing momentum across Canada to expand the role of the RN, as the largest regulated health workforce, to include the authority to prescribe medications and communicate a diagnosis within their knowledge, skills and judgment (RNAO, 2012A). This is separate and distinct from the role of NP, as NPs study for a greater length of time. RNs have been prescribing within the UK for at least two decades. The Government of Ontario has committed to expanding the scope of the RN to include prescribing (Government of Ontario, 2016). RNAO is advocating for an independent model of RN prescribing to ensure timely access to care (RNAO, 2016A). Independent RN prescribing occurs within interprofessional teams and refers to RNs having the authority to prescribe within their knowledge, skills and competencies. It means that RNs will not have to rely on restrictive protocols and/or collaborative practice agreements. Independent RN prescribing is complementary to authorizing RNs to order diagnostic testing and communicate a diagnosis, which are needed to facilitate continuity of care. This will support persons with dementia by providing them with timely access to care in familiar spaces and can reduce the need for unnecessary emergency department utilization. Once implemented within Ontario, independent RN prescribing can serve as a framework for expansions throughout the country.

Another challenge facing provider agencies is ensuring that health-care providers are basing their practice on the best available evidence. Progress in finding a cure for dementia has been slow; and as the population ages, the burden of disease could overwhelm even high income countries (Wingblad et al., 2016). It is imperative that health-care providers across all settings are maintaining and augmenting their competencies in caring for people with dementia according to best practices. Tremendous efforts and resources go into the development best practice guidelines, toolkits and recommendations. Unfortunately, nurses are not always aware that these are available, nor do they always apply the best evidence available. In a systematic review of training manuals for dementia care, Fossey and colleagues (2014) found a major disconnect between education in training manuals and best practices for dementia care. Eighty per cent of the programs were of variable quality and only two per cent were evidence-based. RNAO's multi-faceted best practice guideline program is an effective model that can be used to support the development, implementation and evaluation of evidence-based nursing practice.

2.2 Education and Training of Unregulated Care Providers

Unregulated care providers (UCPs) work alongside and where appropriate, under the delegation of RNs and R/LPNs to provide day-to-day care in a variety of settings ranging from residential care to the community (Simoens, Villeneuve & Hurst 2005). These UCPs have different designations across the country, and are known as personal support workers, health care aides, resident care assistants, or nursing assistants. UCPs assist with older adults' activities of daily living (ADL) such as ambulation, dressing, bathing, meals, and toileting, and provide these services in the context of social interaction and relationships. These activities represent several opportunities to observe people with dementia, monitor the effects of care and treatments and report these observations to supervising registered nursing staff for further investigation (Heckman *et al.*, 2014).

The wide diversity in training for UCPs across this country has resulted in substantial variability in UCP skills and competencies. Several studies conducted in the LTC setting indicate that UCPs face many barriers to providing quality care to residents, including a lack of knowledge (Stone & Weiner, 2001; Castle *et al.*, 2007) and limited training and orientation when starting a new position (Stone & Dawson, 2008). UCP training is extremely variable and might not prepare them with the required knowledge about complex conditions, such as dementia, which leads to lost opportunities to observe, monitor, and report on observations made during care provision, particularly as persons with dementia often present with complex and non-specific symptoms. There is a need for more consistent training standards for UCPs across the country. One way of doing so is through training that includes observing and identifying behaviours, monitoring, and education. Current programs include Gentle Persuasive Approaches©, PIECES© (Hamilton *et al.*, 2006) and crisis interventions and prevention of elder abuse.

Recommendation 4: All RNs must complete mandatory gerontology and chronic disease management training in entry-to-practice curriculum including clinical experience with geriatrics.

Recommendation 5: Support efforts to enable independent RN prescribing in Ontario and use this as a framework for expansion across the country.

Recommendation 6: All unregulated care providers complete mandatory geriatric and CDM training that includes:

- Communication and documentation skills;
- Collaboration and team work;
- Effective management of responsive behaviours; and
- Person and family centred care and services.

Recommendation 7: Provide human and financial resources to support uptake in practice and education, of the most current and relevant evidence to ensure the highest quality, evidence-based care for Canadians with dementia.

3. Housing

As previously identified, fostering living well with dementia means efforts should be made to support persons to remain within their own homes and communities. This requires access to appropriate home and community supports and assistance for care partners (e.g. family members). Well organized home care services, and sufficient and suitable day programs are important staples of supporting aging at home and providing care partners with the resources and supports they need (Landi *et al.*, 2001; Forbes *et al.*, 2008b). Specifically, day programs providing care and services for older Canadians living with dementia

need to be age, cultural, spiritual and gender appropriate and should be offered in rural, non-urban as well as urban areas. Currently, these services are limited, with scattered availability and delivery across the country. Furthermore, it is difficult - and at times impossible - to find out what services are available for what costs and in what area.

When a person with dementia is no longer able to live safely and independently at home, they may consider transitioning to a more supported care setting (e.g., supportive housing, assisted living) to avoid premature or inappropriate institutional care. While each situation is different, this decision is often influenced by health and safety issues for the person living with dementia, their care partner and/or the people around them. Financial issues and the person's preferences are also factors in the choice to move to a different care setting.

Supportive housing is an example of congregate living that links affordable housing to staff that can provide a comprehensive and coordinated package of services and programs to help individuals maintain their optimal level of health and well-being (CMHC, 2015). Such models of living have been shown to promote mental and physical health by encouraging independence, providing opportunities for socialization and friendship, ensuring a secure living environment, and providing opportunities for meaningful activities and social engagement (Lum *et al.*, 2007). Please see Appendix A for a summary of types of housing for persons with dementia.

When people living with dementia and their care partners were asked to identify characteristics of an 'ideal' housing model, their responses included:

- a model which resembles an ordinary home or neighbourhood;
- a space that feels and looks like home; and
- a care model which accommodates varying levels of abilities.

Some factors to consider when transitioning a person with dementia to a supportive/assisted living environment include the following:

- Cost (rent, meals, fees for services)
- Environment (accessibility, security)
- Amenities (outdoor space, recreational areas, guest suites for out of town families)
- Provision of meals.
- Services (types of support, staffing)
- Staff and management (training)
- Location (proximity to friends and family) (Advocacy Centre for the Elderly, 2009)
- Culture
- Religion

Current challenges that impact housing for persons experiencing dementia include:

- Inadequate resources – not enough supportive housing and assisted living available, creating significant waiting lists or inappropriate stays in acute care or LTC.
- Financial constraints – persons and families that are experiencing dementia often have significant financial constraints which demands affordable housing.
- Transportation – adequate housing must be supported by accessible transportation to meet basic needs, attend appointments and maintain social interaction
- Vulnerability – some persons experiencing dementia may have physical and cognitive impairments which can increase the risk of being taken advantage of (e.g. financial abuse).
- Northern/Rural (non-urban area) – access to effective housing options may be limited in these areas.
- Regulation – cost, quality and safety can be limited.
- Long waiting lists.

Recommendation 7: Ensure that all Canadians with dementia, regardless of their socioeconomic status, have access to appropriate housing. This can be done by ensuring that accessible housing models exist that accommodate various levels of care needs and abilities, and resembles living at home.

Recommendation 8: apply a health equity lens in government decision-making to better understand the sociocultural and economic factors that persons with dementia and their care partners experience.

4. Care Partners

The role of care partners, family members, friends and others are critical to support persons living with dementia. In 2011, care partners spent more than 444 million unpaid hours caring for people with cognitive impairment, including dementia (A new way of looking at the impact of dementia in Canada. Alzheimer Society, 2012). Currently, care partners provide up to 90 per cent of the in-home care for persons with dementia (Keating *et al.*, 1999). Although the costs for people requiring care at home are 40 to 70 per cent less than those for people with dementia in residential facilities (Hollander, 2001), costs will rise substantially if care partners are not adequately supported (Hux *et al.*, 1998; Ostbye & Crosse, 1994). Of greater concern, if care partners are inadequately supported, quality of life and care will drop significantly.

Compared to caregivers of older adults who retained cognitive abilities, care partners of persons with dementia are more likely to experience chronic health problems, depression, and social isolation (CSHA, 1994b). Female care partners report difficulties that include insensitive interactions, ineffective or inappropriate resources, and an overall lack of support (Neufeld & Harrison, 2003; Neufeld *et al.*, 2007). Male care partners reported similar non-supportive interactions. Care partners seek a contact person who can consistently be available over time in case they have questions or emergencies, relate with sensitivity to their changing situation, recognize and facilitate the caregiving experience in relation to multiple sources of support, and be their advocate (Neufeld, Kushner, & Rempel, 2007). In a mixed-methods study (Forbes *et al.*, 2008a) examining the role of home care services in dementia care, care partners reported most frequently that they were not eligible for home care services or services were discontinued because of inconsistency of professional care providers. Other issues raised by care partners included insufficient information on the disease process and a lack of guidance on how to manage expressions and behaviours resulting from diminished cognition. Care partners also indicated they faced inappropriate treatments and provision of care; lack of respectful, gender-sensitive, and culturally sensitive care; inflexible programs, especially for employed care partners; and expensive supportive services (Forbes *et al.*, 2008b). All of these challenges emphasize the need for a model that promotes continuity of care and care providers who are willing and qualified to develop trusting partnerships with persons who have dementia and their care partners. Please see Appendix B for more about supports available for informal caregivers.

Issues:

- Uncoordinated Services – multiple organizations provide services but are not managed under one body resulting in gaps in knowing what is available.
- Inconsistent structured support for care partners – care partners need more day programs and respite care available on a consistent and predictable basis.
- Lack of financial support - as dementia progresses and cost of illness increases, care partners face increased care giving needs as well as mounting financial pressures. Canada lacks the necessary mechanisms to provide financial support for care partners so they can recover ‘lost’ wages from their regular jobs.
- With financial support, LTC homes can offer “day openings” to provide day programming, a meal and access to registered nurses. This also facilitates respite care for care partners.

Recommendation 9: Recognize and value the integral role of care partners for persons experiencing dementia and ensure structured support exist, including accessible day programs and respite care.

Recommendation 10: Support efforts that co-ordinate information about local services and programs under one body. Features of the services and programs should be clearly communicated to the public (i.e. provision of meal, length of session, age requirements, etc.).

5. Integration of Health and Social Services

Health is broadly influenced by a number of social, physical, mental and cultural factors. The World Health Organization (2016) identifies five elements needed to achieve a state of primary health care:

- Reducing exclusion and social disparities in health (universal coverage reforms);
- Organizing health services around people's needs and expectations (service delivery reforms);
- Integrating health into all sectors (public policy reforms);
- Pursuing collaborative models of policy dialogue (leadership reforms); and
- Increasing stakeholder participation.

A shift is needed in Canadian health policy from a focus on individual sectors to a broader, integrated model of health and social services. Hollander (2003a) argues that an integrated system will produce cost effectiveness (Hollander, 2003a, 2003b, 2006). The essence of this proposed model is the integration of medical, health, supportive, community, and institutional care into one system. Such a model would ensure that care continues over time and across types of service (Hollander, 2006). This is possible if there is a shift in values, from the current focus on acute care to an inclusive vision of home and community-based care that puts more emphasis on prevention and care co-ordination (Shamian, Shainblum & Stevens, 2006) and includes not only medical care but also social care, health promotion, and disease/disability prevention (Chappell, 2000).

The highest performing health systems in the world have primary care as their foundation, and use it to co-ordinate care delivery (Starfield et al, 2005). Interprofessional primary care delivery that utilizes teams of regulated health professionals practising to their full scope supports an alignment between health and social services. It is critical that health systems across Canada make primary care their foundation. Ontario's Health Links program is one example of a co-ordinated care plan to serve persons with complex needs (e.g. persons experiencing dementia). Health Links work to organize health and social services around the needs of people (Rural Hastings Health Link, 2014). This initiative could be optimized and expanded by explicitly making primary care the foundation upon which a health system is built. Proposals for structural reform are being considered in Ontario to move towards this goal (RNAO, 2016B).

Ontario's interprofessional team-based primary care models, especially community health centres (which also exist across Canada) and NP-led clinics, demonstrate the potential for alignment between health and social services. These settings enable providers to enter into long-term therapeutic relationships whereby all of a person's health and social needs can be co-ordinated, in collaboration with service providers within the community. It is clear that persons experiencing dementia and their care partners want to have consistent access to a single point of contact. Primary care is the setting where this can happen. Moreover, RNs within primary care have the competencies, knowledge and skill to serve as effective care co-ordinators and health system navigators (RNAO, 2012B; RNAO 2014), while NPs should be enabled to serve as lead primary care providers.

Recommendation 11: Advance federal initiatives to support provinces/territories to make interprofessional primary care teams the foundation of their health system. Locate and embed care co-ordination and dedicated care co-ordination RN roles within primary care.

Conclusion

In conclusion, RNAO and CGNA are grateful the Standing Senate Committee on Social Affairs, Science and Technology for the opportunity to contribute to your work. We look forward to seeing our recommendations integrated into your final report. Please contact us should you need any further information regarding our submission.

Appendix A

Types of Housing for Persons with Dementia

Community (Private Housing)

Staying in familiar surroundings provides some security and comfort, which may be particularly important for persons living with dementia. For persons living with dementia, it is particularly important to ensure that their current home supports their independence and allows them to continue to enjoy the activities and lifestyle that they are used to. In addition to supporting the independence and quality of life of persons living with dementia, home modifications can also provide support to caregivers and ensure their safety (CMHC, 2015).

Assisted Living

Assisted living accommodation is designed for people who require only minimal to moderate care to live independently. In this housing option, the accommodation is combined with some supports. These vary but may include meals, housekeeping or personal and health care services. Each province and territory has different regulations and requirements for assisted living facilities. The cost of this accommodation also varies throughout the country. In some provinces, residents are responsible for the full cost of their accommodation and services while in others, the government pays for a portion of the cost. (CMHC, 2015).

There are different types of assisted living that are appropriate for persons living with dementia based on the project size, the level of services provided and whether it is run by a non-profit or for-profit organization. One of the key benefits of assisted living/supportive housing for persons living with dementia is that there is the possibility of tailoring the services to meet their changing needs. In some cases, supportive housing can provide a level of care that is equivalent to a long-term care or nursing home facility. There are different names for supportive housing in the different provinces. For example, in B.C. it is called assisted living, while in Saskatchewan it is called supported independent residences (CMHC, 2015).

Retirement Residences

Retirement residences or retirement homes are another form of assisted living. Most retirement residences are privately owned and operated, although some are owned by a municipal government or non-profit organization. Most retirement homes offer meals, housekeeping, laundry and recreational and social programs in addition to accommodation, but the level of personal care and health services varies significantly as do the costs. For example, some retirement residences are geared toward independent living with the option of paying additional fees for personal care and health services. Retirement homes are often not subsidized by the government. The nature of the regulation of these residences differs from province to province.

In addition, it should be noted that there are other supportive housing models not discussed within this guide aimed at meeting the needs of persons living with dementia who have very complex needs such as persons experiencing homelessness and/or additional mental health challenges. LOFT in the city of Toronto is one example (CMHC, 2015).

Group Homes

Group homes are another form of assisted living. Residents live together in one house and there is usually a small staff to help residents. While this community-based living model is most often used for persons with developmental disabilities, the features of this model also work for persons living with dementia in the early and moderate stages because of its small-scale design, home-like feel, and good staffing ratios (CMHC, 2015).

Long-Term Care Homes

A LTC home is a housing option for people who can no longer live independently and who need 24-hour nursing care and supervision, sometimes in a secure environment. LTC homes offer more personal care and health care services than what is offered in an assisted living facility. LTC homes are regulated by provincial governments and require a license to operate. These homes receive some form of government subsidy, often calculated on a per diem basis, to provide food, accommodation and health care services. In most cases, residents pay for the room and board costs, unless they qualify for a subsidy. There are different names for LTC homes throughout the country but the type of accommodation and level of support services are often the same. For example, LTC homes are called residential continuing care facilities in Yukon, special care homes in Saskatchewan, and centres in Quebec. There may also be differences in costs of LTC in the different provinces as well as in the costs subsidized by the government (CMHC, 2015).

Concept of “Campus of Care”

The *campus of care model* is a relatively new approach, which may include any combination of independent housing, supportive housing, assisted living, residential care and community programs. A campus of care offers an integrated continuum of housing, services and care, allowing residents to remain in a familiar setting and community of people as their needs change. A campus of care model also allows the sharing of amenity and support services, enhancing efficiency and reducing costs (Community Care and Assisted Living Fire and Life Safety Provisions Advisory Committee, n.d.). In many provinces there are difficulties with seamless transitions due to issues with placement coordination (for example, in Ontario local community care access centres do assessments and organize long-term care placement wait lists) (CMHC, 2015).

Appendix B

Available Services to Support Informal Caregivers

Persons living with dementia and their care partners may access in-home and respite care options to provide care partners some time to rest. These may include the following:

- **In-home help** – This refers to care providers that can be hired to provide assistance and can range from a few hours per week to live-in help (provincial home care programs provide supports based on assessed need and there are copayments for some of these) (CMHC, 2015).
- **Day programs or adult day care** – This refers to programs that typically operate on weekdays and offer a range of activities and socialization opportunities. These programs also provide the care partner a chance to continue working (at least part-time) and/or attend to other needs. According to a study by Morton (2010), adult day programs (ADPs) for persons with dementia generally offer supervised and supported social and recreational activities at a location outside the person with dementia’s home. The goal of many ADPs is to help individuals in need of some type of care or supervision to remain active in their communities and out of institutions for as long as possible. ADPs generally offer meals, light physical activity, assistance with daily living, transportation to/from the program, dementia-appropriate recreational activities, medication reminders and, in some cases, varying levels of personal care assistance ranging from simple toileting to showering. Dementia-specific ADPs ideally have appropriately trained health care professionals and many will offer traditional and non-traditional hours of operation. For example, some may offer day-time programs which can allow for care partner relief and the ability to continue working. Evening and overnight programs can also help to address issues like “sun downing” and allow for better sleep for care partners of persons living with dementia who experience nighttime wandering, rummaging, or exit-seeking behaviours (CMHC, 2015).

ADPs come in many forms ranging from lighter care environments as found in elderly person centers to more extensive programming and assistance such as those located in healthcare centres where there is access to health professionals. While most ADPs accommodate persons with early onset dementia occurring before age 65, the majority of programs target seniors aged 65 and older. ADPs may service mixed populations (persons with and without cognitive impairment) or offer only dementia-specific programs (Morton, 2010).

- **Respite care** – This refers to care provided in the home by paid health-care professionals or a short-term stay in a facility (for example, care centre, supportive housing, long-term care home) to provide care partners with some time to rest or attend to other needs. Care partners of persons with dementia, many of whom are seniors with health issues of their own, often provide significant amounts of unpaid care that leave them at risk for their own declining health and possible burnout. Accessing respite programs sooner (as a first line program) than later (as an add-on service) can benefit both the person living with dementia by introducing early preparation and familiarity with the routine of respite and their care partners by providing earlier and more frequent breaks from caregiving responsibilities. Respite care can last a few hours a day in their own home or at an adult day program or for a few days in residential respite facilities (CMHC, 2015).
- **Cluster Care** is one model of care used in Canada where community health care professionals work as teams to bring supportive services to people who live within a certain geographic area (Lum *et al.*, 2007). Another model of care in the community is the Comprehensive Home Option of Integrated Care for the Elderly (CHOICE) in Alberta. In this

model, seniors who have multiple and/or complex health needs and would otherwise be in a long-term care home receive care in a day health centre. These individuals also have access to home care services, respite and treatment beds and 24-hour emergency services (Hollander 2006).

One other approach used in the Netherlands is where teams of health care professionals and case managers provide people with dementia home care services 24-hours a day, seven days a week. Case managers coordinate services from the team and other network partners with the person living with dementia and their care partner. When they need more intensive treatment or observation, people with dementia have access to a 16-bed short-stay clinic (CMHC, 2015).

These different community care options help persons living with dementia stay in their own homes longer. They also provide some support to care partners by augmenting the care they are able to provide as well as providing respite relief either in their own home or through the use of a day centre (CMHC, 2015).

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